



STATE OF DELAWARE
STATE COUNCIL FOR PERSONS WITH DISABILITIES
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The Honorable John Carney
Governor

John McNeal
SCPD Director

BRAIN INJURY COMMITTEE DRAFT MINUTES

March 2, 2020 – 2:00 PM

Smyrna Rest Area Conference Room, Smyrna, DE

15 in attendance of 24 QUORUM PRESENT

PRESENT:

Christine **Applegate**, Nurse Navigator, Neurosurgery, Bayhealth Neurosciences; Linda **Brittingham**, ChristianaCare Health System/Delaware Healthcare Association (CCHS) (DHA); Andrew **Burdan**, Brain Injury Advocate; Tammy **Clifton**, DOL/ DVR, Senior Vocational Rehabilitation Counselor and **BIC Chair** (obo Andrea Guest, Director); Susan **Cowdrey** obo; (Nicholas A. **Duko**, Program Mgr., BCBS Highmark Health Options); Kristy **Handley**, Executive Director (Brain Injury Association of Delaware (BIAD)); Kristin **Harvey**, DDC (obo Michael Harris); Jeffrey S. **Hysan**, Paralegal, Community Legal Aid Society, Inc., Disabilities Law Program; Miguel **Marcos**, TCM Program Manager, Wilmington VA Medical Center; Dale **Matusevich**, DOE, ECE, Education Associate, Transition Services (obo Mary Ann Mieczkowski); Karen **McGloughlin**, Director of Women's Health (obo Dr. Karyl Rattay, Director); Christina **Miller**, Insurance Investigator Supervisor, Department of Insurance/TBI Survivor; Dorothy **Prior**, Psychologist, (obo Marie Nonnemacher) (DDDS); Nancy **Ranalli**, Director of Community Outreach, Easterseals; Carey **Swartzentruber**, Survivor; Karen **Tanner**, Psychologist, DSAMH (obo Elizabeth Romero); and Jamila **Waigwa**, DHSS/DSAAPD.

ABSENT: (6)

Sybil **Baker**, GACEC (obo Wendy Strauss); Megan **Coulbourne**, Director of Therapy Operations, Encompass Health;); Katie **Freeman**, Psychologist, DSCYF/DPBHS (obo Robert Dunleavy); Sue **Gamel-McCormick**, APRN, DHSS/DMS/Birth to Three; Dr. Ron **Sarg**, DCVA/MOAA; and Tiffani **Taylor**, Nurse Navigator Post-Acute Medical Rehabilitation Dover (obo George DelFarno, Director).

ADDITIONAL ATTENDEES: (Not able to vote or count toward quorum)

IN-PERSON – Gilvore Eloi Intern (DVR); Dee **Rivard**, SCPD; Laura Waterland, Esquire, Community Legal Aid Society, Inc., Disabilities Law Program;

TELECONFERENCE PARTICIPANTS: John **McNeal**, Director (SCPD);

CALL TO ORDER

Tammy Clifton called the meeting to order at 2:05 p.m. after a quorum of members arrived and all handouts were disseminated. Tammy thanked everyone for attending and requested everyone to introduce themselves for the record. Tammy announced that John McNeal is attending via teleconference to provide an update and that Laura Waterland from Community Legal Aid, Disability Law Program will give her presentation following the Survivor Update in order to allow her to leave if she needs to attend another meeting.

SURVIVOR UPDATE

- Tammy returned to agenda item III. Survivors Brief -- Survivor Carey began by reminding everyone how he received his traumatic brain injury (TBI). Carey's brain injury was caused by an airplane propeller on the job almost a decade and a half ago when he worked for American Airlines. Carey shared that he struggled with everything and things were getting worse with his family. He reached out for help because in addition to his TBI his wife had a drug addiction issue and the people he trusted found a different place for his children to stay. He is unable to have much contact with his children. Carey had a CT Scan along with other tests that showed that he had high levels of stress which is not good for anyone but especially for TBI Survivors. Carey was dealing with his 3-year son who would hide when the van pulled up to take him away and who would cling to him holding on tight and saying no. As a father that was hard. Carey would experience flashbacks about this stress and thinks about them leaving and not being able to see them every day. With everyone thing that he is dealing with his brain injuries and the added stress of trying to get his wife the care she needed and his children not being able to stay with him, he had to agree to things that he didn't want to in order to get the help his wife needed for her addiction. Carey recently received a neuropsychological evaluation and was told that he is doing well even though he is still troubled with trying to get the right words to come out in the right way and memory issues. Unfortunately, there is no one willing to say definitively that he can take care of his children. The person he is meeting with is doing his counseling in addition to some testing. Carey welcomes anyone's input that will help him with where he is at currently. Everyday gets harder for him with the stress he is dealing with and missing his children. Carey is sure that he is not alone and that other parents deal with this also. He feels like he has to second guess everything that he does right now, and it is creating a snowball effect. Are there other organizations that can help him. His children are currently in New York and are expected to come home in a few months. He wants to ensure that his children can stay with him and that his family does not say that his children can't. There are other people with brain injuries

and other types of disabilities out there. No one should be kept away from their children just because they happen to have a disability.

- After receiving permission from Carey, John told Laura Waterland and the Brain Injury Committee (BIC) members some of the things that Carey shared with him including that the place his wife is receiving her addiction treatment is in New York. Traditionally persons receiving addiction rehabilitation stay at the location for several months to a year and then are eligible to receive additional time. The problems that Carey faces are with the Grandparents who harass him and tell him that he cannot see his children, cannot take them out of the facility, and that he cannot just come to New York to see his children.
- Kristy shared information with Carey and the other BIC members about a patient that she met who had a brain injury and was getting ready to lose their children just because they had a brain injury. She assured him that he is not alone and that this is an important issue that Delaware needs to address.
- Tammy thanked Carey for sharing.

ADDITIONS/DELETIONS TO THE AGENDA

Tammy inquired if there were any additions, changes or deletions to the agenda.

- Dee advised that the first change to the agenda was already noted on the agenda that the Committee would move Laura Waterland's presentation up to following approval of the agenda and minutes of the last meeting.
- Carey made a motion to approve the agenda as amended, Christine Applegate seconded the motion and voting members in attendance unanimously approved.

APPROVAL OF PREVIOUS MEETING'S MINUTES

Tammy moved on to agenda item IV asking if everyone reviewed the minutes of the February 3, meeting. Tammy called for additions, corrections, or deletions to the minutes.

- Hearing none, Jeffrey Hysan made a motion to approve the minutes of the 02/03/2020 BIC meeting as prepared, Christine seconded the motion and voting committee members in attendance unanimously approved the motion.

LAURA WATERLAND PRESENTATION

Laura provide BIC members a presentation entitled "**Americans with Disabilities Act (ADA), Rights of Parents with Disabilities.**"

- Laura Waterland works for Delaware Community Legal Aid Society, Inc. (CLASI) as their Disabilities Law Program (DLP) Project Director. CLASI is a non-profit legal program. The DLP receives 8 federal grants. TBI, Developmental Disabilities, Administration on Disabilities (AoD), Voting Access, Assistive Technology, and two Social Security related grants to remove work impediments. They recently received a new grant to work on the monitoring of Social Security benefits quality of services.

They take referrals and do civil legal services but not criminal. They have limited resources that prevent them from accepting any kind of cases. The only custody cases they sometimes take are when the state is a participant or actor. Laura advised that it is best to call into their intake to determine if they take specific cases. CLASI also helps persons with disabilities through their Housing unit and elder law unit. The CLASI centralized intake system obtains all the appropriate information before the case is assigned to a unit and then they proceed from there.

- Laura reviewed the five titles of the ADA for members.
 - Title 1 – Employment
 - Title II – Public Services (State and local governments)
 - Title III – Public Accommodations and Services (Operated by Private Entities);
 - Title IV – Telecommunications; and
 - Title V – Miscellaneous (Enforcement and Anti-Retaliation)
- Laura covered each of the above titles in more detail reviewing what Title II - Public Services covers sharing that it is important to look at actual physical access in addition to the programmatic access. CLASI tries to enforce the Olmstead obligations. Laura reviewed what Title III of the ADA covers e.g. Public Accommodations advising that housing discrimination is enforced under the Housing Administration Rules. She further clarified that the airlines have their own rules as does Telecommunications.
- Laura reviewed the definition of disability according to the ADA advising that there must be an individual analysis of whether an individual has a qualifying disability.
- Laura then provided BIC members with information on the “Rights of Parents with Disabilities” stating that the U. S. Department of Justice and the Department of Health and Human Services Office of Civil Rights have been paying attention to the way state and local government agencies treat parents with disabilities.
- Laura provided information on a National Council on Disability Report in 2012 that documented discrimination against parents with disabilities in custody proceedings and when involved with state child welfare agencies. Laura advised that the Rights of Parents with Disabilities is an evolving area and that there is a lot of concern over the prejudices and biases from state welfare agencies involving persons with disabilities being very badly discriminated against because of their disability.
- In 2015 a technical assistance letter came out from the U. S. Department of Justice (USDOJ) and the U.S. Health and Human Services (HHS) cited Massachusetts for violating the ADA. In Late December, Oregon had the same issues where the State welfare agency had not done anything to help reunite the family. The National Center for Disabilities (NCD) report link is contained within the document she shared. Oregon is currently under monitoring right now. Laura briefed members about a case she had a few years ago relating to a grandson whose caregiver had

significant disabilities. The state did not have any guidance because they did not have any policies in place. In Delaware, we need to work on getting agencies to have formal written policies adopted. With cases involving Title II of the ADA there is a pretty strong argument. If there are families involved with Social Services, they receive a host of services. Unfortunately, the same cannot be said for individual parents. However, if services are available to **any parent**, they must be available to **all parents**. Laura stressed that it is important for agencies to do individualized assessments. The agencies must be able to assess whether the risks can be eliminated through the use of supports and assistive technology for example. The legal avenues are much clearer when the state is involved. However, the ADA doesn't apply in disputes between two parents or family members. Unfortunately, it is not illegal to be mean or to make up stuff. The application of the ADA is pretty-limited with state law governing custody. Each parent has **equal rights** to the custody of the child.

- Laura advised that when the courts get involved, they use the best interests of the child standard. The courts can look at the mental and physical health of both parents as well as the child. The courts have significant leeway. Delaware courts use the best interest standard and courts are allowed to consider the mental and physical health of both parents. It is unclear how much the ADA might impact the decision of the judge. Frequently judges will make assumptions that the child will be a caregiver and are oblivious to the availability of supports that a child or parent may already use or the supports that are available to the parent with a disability. One strategy is to work to get the law changed to remove disability as a factor unless it is done with clear and convincing evidence. Laura provided some practical tips and stated that unfortunately, it is not uncommon to see disabilities raised during custody disputes. She advised that people with disabilities be prepared that there may be some skepticism about their ability to parent. How can you keep your child safe? She included some of the resources that she used in creating her presentation and she has them with her if anyone is interested.
- Kristin felt that the BIC members need to work to educate the Legislators and courts concerning the rights of individuals with disabilities.
- John thanked Laura for providing some really great information and shared that it is something that he thinks about every day. John talked about the cognitive challenges that he sometimes has because of his brain injury. Thank you, Laura, for providing excellent information.
- Nancy stated that Carey doesn't know what his rights are as a parent. Carey shared that he does not have a court order because they completed a voluntary agreement. The signing of his agreement was preceded by a meeting with 14 other people in attendance for the meeting that he wasn't even invited to attend. It is a communication issue. Nancy and Karen do not see any reason why Carey cannot parent. Carey advised that he spoke with an attorney who drew up a plan. Laura

advised Carey that he has to decide what his bottom line is. Don't sign anything that you haven't been able to discuss. Carey needs an advocate to ensure that his voice is being heard.

- John asked Laura if her office can participate as an advocate. Laura advised that CLASI refers these types of issues to the private bar for custody disputes.
- Carey advised that counselors tell him that he needs a regimented plan because of his short-term memory being the problem. Carey stated that as a survivor you trust that what you are being told is what you need to do. Karen McGloughlin stated that Carey has as much right as anyone else has as a parent. Laura agreed stating that it sounds like Carey has a voluntary custody agreement in place and that his in-laws have no rights whatsoever. Carey's children are going to school in New York for this year.
- Tammy told members that the BIC now knows where the work needs to be done and that she hopes that Carey has a better idea of his next steps.

OLD BUSINESS

Motorcycle Helmet Advocacy

Tammy moved on to Section V. Old Business on the Motorcycle Helmet Advocacy at 3:00 p.m. requesting an update from Director John McNeal on the Motorcycle Rider Education Advisory Committee that he mentioned during our last BIC meeting.

- John communicated by emails and Rep. Lynn is comfortable with the legislation moving forward with the caveat of a grandfather clause for the people already licensed with the law only applying for new riders. The challenge is finding a sponsor on the Senate side. Senator Cloutier liked the idea of 30 years and younger. John provided her costs that Dee found from NHTSA as to the costs for people wearing helmets vs. not helmets. That is what is really moving the people at this point. He has not had an opportunity to reach out to many Senators. He is happy to continue to reach out to other potential sponsors when we get back in session to see if there are others who are willing to look at the bill one way or the other. John asked BIC members if the only way the bill can get introduced this year is if it applies to people 30 and under if they agreed. Committee members agreed that it was more important to get it on the books and that they could always amend it later. Mandate helmet usage for people wearing helmets if they are 30 years and younger. It becomes habit forming and God forbid that anyone under the age of 30 lay a bike down. After 30 is a perfectly legitimate point. Karen asked if Sen. Cloutier has statistics. John stated that it is actually older people who are having the fatal injuries. It is going to get that point across to older riders. Rider's being grandfathered won't be affected. Nancy asked if 18-year old individuals are getting their MC Rider licenses. Is it more people in their 30s and 40s? John stated that it was a good question. Is it a mid-life crisis, there are lots of clubs out there now to join and be a part of? The inclination is that the ones that you see most reckless about lane-splitting and some of the more

provocative riders with crotch rockets. They have a lot more torque and ability to slide in and out of traffic. Now a days you have husbands and wives riding with technology that makes it desirable to ride together. Under 30 sounds reasonable to Senator Cloutier. She did not like the idea of the broad legislation mandating everyone to wear a helmet. John has a meeting with the Motorcycle Rider Education Advisory Committee next Monday. John wants to be able to provide some of the general statistics. If it is introduced in the House never has the point been made that you are the safety and homeland security committee not the personal freedom committee. Karen inquired if John can request the average age of MC licensees from the Division of Motor Vehicles (DMV). John will also reach out to OHS for info. Helmet laws were enacted because of federal laws and legal adult requirements. Should be able to get some statistics. States are doing a lot of different things. Very conservative states are even enacting the laws by age requirements. Having insurance is a sign of responsibility. John is trying to obtain Medicare data providing the costs of his TBI related treatments. John has 4 friends who had MC crashes and had spinal cord injuries and TBIs. Need a motion to consider amending the legislation to include mandating the wearing of a MC helmet for anyone 30-years of age and under. BIC members suggested increasing auto insurance coverage if helmets are not worn. The majority of TBI survivors receive Medicaid benefits and it might be beneficial to require carrying increased insurance coverage unless the riders' wear helmets. Members agreed to have John work on this issue as part of a steppingstone approach to increasing motorcycle helmet usage in Delaware. Karen made a motion to move forward with legislation requiring Delaware MC riders who are 30-years of age and under to wear helmets when riding motorcycles and for a second piece of legislation containing a grandfather clause for currently licensed riders at the time of the bill's passage. A separate version of the legislation will include a request for the addition of a \$15.00 on any motorcycle violations to be added to Delaware Brain Injury Fund for the purpose of providing outreach, education, support, and services to Delaware's brain injury patients. Ron seconded the motion. Tammy called for all in favor and inquired if any members were opposed or abstained from voting. Hearing no opposition, the motion carried. The BIC members agreed to working two different versions of the bill to see which version we can get passed. Jeffrey will work on preparing the revised legislation asking for \$15.00 for violations added. It is an ask, and it doesn't hurt to ask. Set this up as a separate bill that includes "Whereas" clauses. To be realistic this might not incur

any problems being passed. Sidebar comment - ask about some of the personal injury laws with respect to driver's license and motorcycles.

COMMITTEE & SUBCOMMITTEE UPDATES

- **Motorcycle Helmet Safety Survey Ad Hoc Working Group**

- Karen McGloughlin felt that Katie did a great job creating the questions.
- Karen updated everyone on the status of the Survey Monkey motorcycle survey stating that she was under the mistaken belief that all she had to do was access Survey Monkey and type it up but was informed by her agency that it now has to go through the Division of Public Health (DPH) Workforce Development Process. Karen asked committee members if while waiting on her agency's process to get the questions posted on Survey Monkey if they want the questions posted on the SCPD Website. The Beauty of Survey Monkey is that they analyze the responses whereas placing them on the SCPD website would require manual analysis. She recommended waiting. Dee advised that it will require significant work from the Department of Technology & Information to turn the MS Word surveys into Secure Mail Utility Gateway (SMUG) forms for online input and that both processes would probably be accomplished at approximately the same time. Karen is going to try to mitigate the editing that Public Health is going to do to the surveys. They are trying to make it all into one survey with dropdowns for the different sections. They will try to keep them as comparable as possible.
- Meanwhile, the survey posting is in-progress. It is okay to make copies to share with people and organizations that you know to get them to complete the surveys and submit them.
- Karen advised that the idea to post an online petition is tabled at this time.
- John clarified that the Cabinet Secretary of the Department of Safety & Homeland Security is not the Chair of the Police Chiefs Council. John also announced that the Governor nominated Colonel McQueen for confirmation later this month to fill the role left by Secretary Coupe when he resigned to become Chief of Administration at the Delaware Department of Justice.
- John also shared that when he wrote in his weekly report about looking at the helmet law and the different demographics that Secretary Coupe really embraced the idea of requiring helmets for riders 30 and under.

John added that it would be nice to obtain an endorsement from the Delaware Police Chiefs Council and Emergency responders.

- **TBI Fund Application Review Committee Update**

- Nancy Ranalli stated that the Traumatic Brain Injury (TBI) Fund Committee has not met since our last BIC meeting. However, the committee did receive two applications that committee members present reviewed prior to the BIC meeting that they are required to vote on at this time.
- Nancy requested a vote on application file TJC-2019-23. Following a motion by Nancy, that was seconded by Kristin, TBI Fund Application Review committee members present unanimously voted to fund this application request estimated at \$1,070.
- Nancy called for a motion to approve the BMS-2020-02 funding request. Following a motion by Nancy, that was seconded by Kristin, TBI Fund Application Review committee members present unanimously voted to approve the \$2,800.00 for this funding request.

- **Data Development Subcommittee (DDS) Update**

- Karen McGloughlin stated that Dee is amazing and that she has been diving into the data that DHIN has given us to begin analyzing the data.
- Karen also shared that while the DDS members were hoping to provide legislators data on TBI injuries by district, there is no real organized way that legislative districts are divided. There is no real way to go to each Legislator to determine how much brain injuries are costing within their individual districts. We are trying to find a work-around. Karen advised that we can divide it by county in order to complete tabulations by county. It is a more generic number that will be good enough to talk to people. Karen also shared that Dee received an offer of assistance from the Delaware Healthcare Information Network (DHIN).
- Dee provided members with a quick update on 2018 TBI data that she completed analysis on in order to provide members some idea of the types of statistics available from the data. Dee advised that we do not yet have data to compare acquired brain injury (ABI) statistics to traumatic brain injury (TBI) statistics. The data that she reported on only involved Delaware TBIs not ABIs.
- Dee shared recent news that she received from Victoria Couhinan stating that Victoria looked over the TBI historical documents that Dee sent her in light of a recent discussion during the State Council for Persons with Disabilities Council (SCPD) meeting. Victoria stated that the TBI Fund was established through the Grants-in-Aid bill in 2013, not in epilogue, which means that there is a bill that governs the fund's creation, although it is not part of the Delaware Code or easy to find by someone searching for it. The

creation through the Grants-in-Aid bill still exists today and the fund remains (unlike other things created by epilogue that cease to exist at the end of the fiscal year unless put in the next year's epilogue), as long as the General Assembly continues funding it in future appropriation bills and as long as the funds don't revert to the General Fund (which they have not yet done, due to re-allocation in each term of the General Assembly since its creation). Apparently, the General Assembly has used this formula for money intended for specific purposes that they want to re-consider annually whether to continue funding.

- In addition, the language in the Grants-in-Aid bill creating the fund stated that the "SCPD may adopt reasonable policies and procedures pertaining to the operation of the fund, including program eligibility . . ." is broad enough that it can be read to include using the funds allocated by the General Assembly to market the fund to those that the funds are intended to assist. The SCPD has been vested with the authority to establish the procedures to operate the fund, so that language would justify the SCPD's vote to use a reasonable amount of funds on a marketing campaign. She advised that SCPD should use the state's central contract for advertising, which has multiple vendors to select from, and to obtain quotes from several of the vendors for the specific type of marketing that the SCPD decides they want to do. She also advised that SCPD should be sure to only spend a reasonable amount of the overall allocation on marketing or other administration of the fund, in relation to the amount of funds allocated annually to the fund.
- Victoria also spoke to DSHS's DAG and who shared that many of the DSHS's grant funds/programs are set up the same way – created in the Grants-in-Aid bill and then funded in future appropriations bills. She also confirmed that other funds have similar language about the governing board being able to adopt procedures to operate the fund, and those funds use a portion of the allocated money for administration/advertising of the fund (for instance, the marketing of the fund that provides text 911 service that is on the radio now).
- Kristin shared that the Delaware Developmental Disabilities Council (DDC) is using Alloysius Butler and Clark who are approved through state contracts for their marketing and outreach efforts. John announced that he is comfortable with using 10% of the TBI Fund as a reasonable portion to promote outreach and marketing of the fund. He stated that the most effective portion of outreach is testimony from Survivors and members.

- **Prevention and Outreach Subcommittee (P & O)**

- Christine Applegate summarized today's meeting that met prior to the BIC meeting by stating that the subcommittee members agreed to go out to introduce the TBI Fund again by mailings and in person as well as providing educational materials for Survivors and providers on the SCPD website at: <https://scpd.delaware.gov/brainInjury.shtml#tabsBox4>.
- Christine shared that some of the subcommittee members are interested in doing some outreach at professional sports leagues in Delaware and that another member agreed to discuss the TBI Fund on "Weller Does Delaware"

ACTION ITEMS

- Advocate for Brain Injury Survivor Rights (BIC & BIAD);
- Attend the Motorcycle Rider Education Advisory Committee (John, Tammy, Ron, Kristin and Dee);
- Upload survey questions to Survey Monkey and share on the SCPD website. BIC members should also share the Survey Monkey link once everything is posted. (Ad Hoc Survey Subcommittee);
- Obtain Medicaid statistics (John);
- Analyze sample data from DHIN (DDS).

NEW BUSINESS

- Having lost a quorum, this agenda item is tabled until the next BIC meeting.

ANNOUNCEMENTS

- Kristy Handley reminded everyone about the Brain Injury Association of Delaware's 29th Annual Brain Injury Conference this Thursday.

ADJOURNMENT

- Christine made a motion to adjourn that Kristin seconded. Tammy called for discussion and hearing none, called for a vote by committee members present who unanimously approved the motion to adjourn at 3:45 pm.

NEXT MEETING

- The next scheduled Brain Injury Committee meeting is scheduled for **Monday, April 6, 2020 at 2:00 p.m.**, and is being held virtually by Zoom Meeting. This meeting is accessible by desktop, laptop, and tablet computers, smartphones, teleconference with chat via computers without video capabilities and by regular teleconference.